

Supporting Families During Chronic Illness

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Although it is the individual who is diagnosed with chronic disease, the entire family experiences life with the illness. Chronic illness is a multidimensional experience; the most efficacious support for families living with chronic illness will also be multidimensional. This paper summarizes what is known about support for individuals and families in which an adult member is living with chronic illness such as cancer, heart disease, or diabetes and suggests propositions that relate the demands of illness to the nature, source, timing and outcomes of support for families living with chronic illness.

Chronic Illness

The experience of chronic illness involves living with one or more diseases that are long term, are not curable and/or have residual features, imposing limitations on an individual's functioning and requiring special adaptation on the part of the individual with the illness (Dimond & Jones, 1983). The course of chronic illness varies greatly; some types of illnesses begin insidiously; others as catastrophies. Although the course of the illness may be relatively stable or punctuated by exacerbations, remissions and/or recurrences, the duration of chronic illness is characteristic: individuals and their families must cope with the illness for their remaining lifetime together.

What is most noteworthy about chronic illness is the variability of responses to the same disease. Not only are there dramatic differences among diseases, their onset and course, but there are also dramatic differences in how different individuals experience the same disease. Responses to chronic illness may vary according to the age and developmental stage of the person (Hamburg & Inoff, 1983). Metabolic processes, psychological and cognitive tasks and family life cycle-stage may all influence adjustment to chronic illness.

The Demands of Illness

In an effort to understand the multidimensional and often idiosyncratic experience of chronic illness, Haberman, Packard, and Woods (1985) proposed the construct "demands of illness." Specifically, demands are the events or experiences that individuals and families attribute to the illness that may tax the family's personal and social resources and thus the family's well-being. Individuals experience demands generated by the direct effects of the disease and its treatment such as decreased social activity, loss of strength and fears about the effects of the disease. Some demands involve disruptions in the way one perceives the world (e.g., disruption of a sense of predictability and personal integrity). Still other demands occur in transactions with the environment (e.g., with the social network and with health services). Moreover, families experience demands in dealing with the extended family, work and school environments as well as pressures to change internal processes such as decision making and integration of family roles.

Demands are the perceptions of individuals; they may vary during the course of an illness. Initially the demands may reflect the direct effects of disease or therapy, whereas later in the illness the demands may reflect personal disruptions and family adapta-

tion. Moreover, individuals within the family may have shared or divergent views about the nature of the demands (Haberman et al., 1985; Munet de Vilaro, 1984; Germino, 1984; Gotay, 1984). In summary, the response to chronic illness in a family member may depend on the nature and course of the illness, itself, as well as on the demands perceived by family members.

Support

Supporting families who live with chronic illness requires recognition of the complexity of the illness experience as well as the nature of social support. Common dimensions of support provided by the family for individuals with chronic illness include: access to a supportive spouse (Medalie & Goldbourt, 1976; Dimond, 1979; Funch & Marshall, 1983); family cohesiveness (Bloom, 1982; Bloom & Spiegel, 1984; Dimond, 1979); family expressiveness (Dimond, 1979); supportive behaviors of family members (Schafer, McCaul, & Glasgow, 1986); and family interactions specific to self-care regimens (Schafer et al., 1986). Dimensions of support involving opportunities for social exchange outside the family include: access to a confidant (Dimond, 1979; Bloom, 1982); amount of social contact (Bloom, 1982); organizational involvement (Funch & Marshall, 1983); number of friends or relatives in the person's network (Funch & Marshall, 1983); and participation in leisure activities (Bloom, 1982).

Little is known about the type of support helpful to the family as a whole or whether supportive services can be provided and are appropriate for the entire family. Studies of families as a unit have focused on their use of social support as a means of coping. Stetz, Lewis and Primomo (1986) found that families in which the mother had a chronic illness coordinated their own internal efforts to manage more than a third of their problems. Internal household management of problems included provision of concrete aid, affirmation and physical affection among family members, as well as alteration of household roles and routines. Families sought information or services from outside the household for about 20 percent of the problems they faced. These authors suggest that the types of support appropriate for families include information about a problem, an opportunity to discuss concerns with both professionals and nonprofessionals and spiritual support.

The perception that social resources exist and can be mobilized when needed may not correspond to the actual use of supportive resources or their actual availability. Perceptions of

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support may be linked to the individual's sense of self-efficacy or personal and social competence (Woods, Draye, & Mitchell, 1988) as well as the propensity to view life from a positive or negative perspective (Antonovsky, 1979; Watson & Clark, 1984). Transitory moods, well-being and attitudes also influence perceptions of support. A psychological sense of support is nourishing as it fosters the belief that individuals will come through for the family (Gottlieb, 1985). Individuals or families with a high level of well-being will have high self-esteem and perceive that they have access to a high level of social support.

At the same time, there is increasing evidence that the balance between support needs and availability changes throughout the life course (Kahn & Antonucci, 1982). For example, Jenny (1984) reported that young adults perceived the greatest support while the aged reported the least support. For middle-aged adults, the spouse was most frequently identified as a source of support, but almost half of the older women indicated a lack of spouse support. Thus age seems to play an important role in the availability of support. Ellison (1987) outlined different support needs according to the stages of psychosocial development and suggested that what individuals require and they perceive as being supportive varies in different stages. Social support as currently defined in the literature, then, may be most useful only during certain stages of development.

Quantity and Structure of Support

Quantity of support is often assessed by summing the number of individuals who can provide it or by scaling the amount of support provided by network members. Social network measures typically include the structural characteristics of the individual or family's network such as size, density, multiplexity and reciprocity (Mitchell & Trickett, 1980).

Some contend that the ideal personal network should be fairly large, with low density, heterogeneous network structures and a balance of uniplex and multiplex relationships (Albrecht & Adelman, 1984). Pattison and Pattison's (1981) study of schizophrenics and nonschizophrenics' networks found that the number of significant ties for normal individuals was approximately 25, whereas the average number for schizophrenics was 8 to 12. Furthermore, the nonschizophrenics' networks were characterized by a reciprocity of both instrumental aid and affect, whereas schizophrenics were unable to reciprocate either. A larger network with dense but unconnected, weak linkages among members creates opportunities for access to more information, allows one to try new roles and allows one to alter one's self-esteem by being exposed to more diverse persons.

Women have more extensive and varied networks than do men, who generally rely solely on their spouses for support (Antonucci, 1985). Antonucci and House (1983) found that women reported both providing and receiving more support than did men and were more positively influenced by the provision of support. Gender differences in networks may explain why the spouses of male cardiac patients, often the sole providers of support, report higher stress levels than do their mates (Gillis, 1984; Croog & Fitzgerald, 1978) and why males with diabetes perceive receiving more support from their spouses than do females (Ahlfield, Soler, & Marcus, 1985).

Sources of Support

Little attention has been given to the sources of support for families living with chronic illness. Lin (1986) proposed that particular sources such as confidants, friendship networks and the community can best provide certain types of support. Specific support resources may include the spouse or partner, household family member, extended family, friend, co-worker, support group or organization.

According to Lin (1986), expressive support is best provided

by individuals with whom one has strong ties and who are like oneself. Instrumental support can best be provided by those to whom the individual has weaker ties and who can link the individual to a broader, more diverse social network. This suggests that professionals should provide different types of support than family and friends. Although Lin does not specify who can best provide information, information sources might include professionals who have theoretical and practical knowledge or nonprofessionals whose experience equips them as experts. The professional who is prepared to help families manage emotional distress through creating a strong therapeutic relationship could also be an appropriate source of emotional support.

Lin (1986) suggested that confiding partners or confidants can provide binding support in which reciprocal and mutual exchanges are expected. The social network, through which the individual has access to a relatively large number of other individuals, provides bonding through kinship, a shared working environment and friendship. The community provides integration, or belongingness. It is through the extended family, the social networks of individual family members and community resources that the family as an entity can obtain support.

Whether or not the extended family is best equipped to provide emotional support depends on the nature of existing relationships, their accessibility and the expectations of reciprocity. The social networks of individual family members can provide both expressive and instrumental support—also depending on the nature of the relationships. Families who have low-density, heterogeneous network structures are best equipped to provide instrumental aid and ongoing emotional support. When various parts of the network inflict demands on the family, the family is free to obtain support elsewhere (Albrecht & Adelman, 1984).

Networks of individual family members may be overlapping or quite distinct. In families in which there is a high degree of overlap of individual family members' networks, there may be greater support for the total family. For example, network members linked to both the adults and children in the family are best equipped to respond to the needs of everyone in the family. Finally, the greater the diversity in the social network the greater is the likelihood that someone can provide for the range of demands the family faces.

Both professional and social support from one's network have been found to be helpful to psychological recovery for women with breast cancer (Funch & Mettlin, 1982). Support from one's spouse was a critical variable in the adjustment of women after mastectomy (Peters-Golden, 1982). Primary sources of instrumental and emotional support for families in which one member was recovering from a myocardial infarction were grown-up children and friends and neighbors both during hospitalization and three months later (Dhooper, 1984).

Both the nature and source of support affect how it is perceived. Dunkel-Schetter (1984) found that emotional support was perceived as being most helpful by 82 percent of cancer patients, whereas information, direct aid and appraisal were considered to be less helpful. Emotional support was considered to be equally helpful whether it came from family, friends or medical personnel, while lack of emotional support from health care providers was evaluated as unhelpful. Information and advice were perceived as being helpful if they came from health care providers but unhelpful if they came from family or friends. The helpfulness of tangible assistance, according to Dunkel-Schetter, did not vary depending on who provided it. Support from a health professional, like that from a family member, seems conspicuous when it is absent. For example, Taylor, Falke, Shoptaw, & Lichtman (1986) found that a consistent characteristic of cancer patients attending support groups was a negative experience with the medical community.

The specific support source (kin vs. nonkin) may not be as important for health and well-being as is the nature of the provider-recipient relationship. Albrecht and Adelman (1984) suggested that individuals seek social support from those with whom they perceive less relational uncertainty (provider is able to gauge how to be supportive), from those who share a stressful context (provider has insight into subtle stresses) and from those of higher status in stressful work contexts. Further, individuals feel supported when the affective and/or instrumental aid they receive improves their ability to relate to others in a changed or new situation, if it satisfies their need for belongingness, and if it increases their ability to understand difficult situations such as illness.

It is not yet clear who will be available to support families as they assume supportive roles for the ill member. Most professional nursing services are directed toward the diagnosed individual and the individual, not the family, constitutes the unit of care. However, professionals can provide the types of support that families have said they need: information, opportunities to share concerns and support services. These types of support resemble the support provided through what Lin (1986) calls weak ties; the best source of expressive support for the family may be those with whom the family has strong ties—extended family members, close friends and those who are similar to the family such as other families living with the same illness. Thus another role for professionals may be linking families with informal and formal community supports that complement or supplement their resources (Ellison, 1983).

Timing of Support

The timing, frequency and duration of support have been ignored until recently. Using a model of stressful situations and transitions, Jacobsen (1986) proposed sequencing support, noting that in a crisis, emotional support would be most efficacious, while cognitive support should be provided during transition. Material support is important during times of resource deficit. However, individuals with chronic illness may experience combinations of crisis, transition and resource deficits at any time, making complicated the sequencing of specific types of support.

Nevertheless, many researchers have suggested that illness experiences can be characterized by the phases occurring between initial diagnosis and some end point (Fiore, Coppel, Becker, & Cox 1986; Giaquinta, 1977). For example, Northouse (1984) described a family's adaptation to cancer in one of its members using three phases of the illness: initial, adaptation and terminal. During the initial phase, the family members were not the focus of care, yet they needed to communicate with health professionals and others in their lives. In addition, they needed to manage their own emotional distress. During the adaptation phase, the family members needed to adjust to changes in roles and life-style, meeting the needs of well family members as well as the needs of the ill member, and living with uncertainty. During the terminal phase, family members needed to communicate about death, provide care and support to the dying family member and deal with feelings of separation and loss.

Lovejoy (1986) also found that the family members of patients hospitalized for cancer exhibited responses that changed over the course of the hospitalization. Initial shock at the illness was followed by uncertainty, accommodation, immersion in the patient and awareness or seeing beyond the immediate situation. Therapeutic nursing actions identified by the families were validation of worth, provision of assurance and preparation for the unknown.

Dhooper (1984) found that at the height of the MI crisis, emotional and instrumental help was needed and provided, and perceived by the majority of families being as "somewhat" to

"very" helpful. However, this help was no longer available to the extent needed at one month after the patient's discharge from the hospital. Dhooper theorized that sources of help may consider that the crisis is over when the ill person returns home. She also found that social class was related significantly to the amount of social support received during hospitalization. Families with the lowest socioeconomic status received low or only moderate assistance despite their greater needs for instrumental support.

The need for some types of support appears to be constant throughout an illness. Gotay (1984), for example, found that family members were concerned with disease recurrence or death in both the initial or early diagnostic phase and the late stage of the disease. Finlayson (1976) found that MI patients whose spouses received more assistance (consisting of family visits and instrumental aid initially and over the course of the illness) had more favorable outcomes than did other patients. These results suggest that certain types of support may be essential throughout the illness and that other types have time-bound effects. Moreover, factors such as the family's resources, personal characteristics (e.g., competence, coping behaviors, developmental stage) and the individual or family's values and perceptions also influence the need for support at any given time.

Outcomes of Support

Investigators of chronic illness have tended to focus on the experience of the individual living with chronic illness rather than on the experience of the family. The exception has been studies of caregivers or partners of the chronically ill (Croog & Fitzgerald, 1978; Dimond, 1979; MacElveen, 1977; Sexton & Munro, 1985; Stetz, 1986) and work in progress with school-age children and partners of women with diabetes and breast cancer (Lewin, Woods & Ellison, 1986).

The outcomes of support most commonly addressed in the literature on chronic illness include health of the individual with the illness (defined as clinical outcomes such as the presence or intensity of symptoms), functional health (as indicated by the ability of the individual to perform activities of daily living such as occupational or household tasks) and adaptive outcomes (e.g., coping efforts or adherence to a treatment regimen) (Starfield, 1979). There have been no studies that address the eudaimonic conception of health, or exuberant well-being (Smith, 1981). Few studies have examined the influence of support on family adaptability and cohesion, parent-child relationships or adult partner relationships.

In the enthusiasm for the positive health effects of social ties, many researchers have ignored the potential negative health effects of using support. The possibility of incurring indebtedness through the reciprocity assumed when one accepts support requires careful analysis. Tilden and Galyen (1987) assessed the cost of social support by asking individuals to report the cost of providing support, imbalance in giving and receiving in a relationship, conflict, and the inequity/equity balance in relationships. Likewise, Barrera (1981) asked respondents to consider relationships that were conflict-riddled but also provided necessary support to an individual.

That acceptance of support incurs future obligations is evident in studies of low-income families (Belle, 1982; Stack, 1974). In particular, Belle demonstrated that stress associated with family and friends increased with their proximity and frequency of contact as well as with contributions such as borrowing or lending food items, borrowing or lending money and helping each other in other ways. The women in Stack's study experienced limited goal attainment once they became part of a network of obligations because the consequence of accepting support was a reciprocal obligation.

Schizophrenics who were unable to reciprocate in the sharing with others of burdens, affect and resources experienced a deterioration in their personal network and increased psychopathology (Lipton, Cohen, Fischer, & Katz, 1981). Rook (1984) found that negative social interactions decreased well-being more than positive interactions enhanced well-being because negative interactions were more rare and thus more salient. Moreover, Rook suggested that some individuals avoid costly interactions as a survival mechanism. Should avoiding costly negative interactions cause individuals to hide their problems, their health problems could worsen. Enforced social dependency, a construct proposed by Benoliel, McCorkle, and Young (1980), may reflect the deleterious effects of accepting support when one has no choice.

The few studies addressing family members or caregivers of ill individuals underscore the cost of providing direct aid to an ill family member by a spouse who is often both the caregiver and presumed source of support (Croog & Fitzgerald, 1978; Klein, Dean, & Bogdonoff, 1986; Stetz, 1986; Vachon et al., 1977; Worcester & Quayhagan, 1983). Studies of support for caregivers suggest that the caregiving tasks that confine the caregiver either temporally or geographically constitute burdens (Johnson, 1985). The burden associated with confinement of the caregiver could be relieved by provision of personal aid services, supportive equipment enabling greater self-care and respite services (Montgomery, Gonyea, & Hooymann, 1985). Moreover, caregivers of persons with Alzheimer's disease have been shown to reduce significantly their burden through use of spiritual support and the extended family (Pratt, Schmall, Wright, & Cleland, 1985).

There also is evidence of the negative effects of the family's presumably supportive activities. Dimond (1979) found that family cohesion had negative effects on social functioning of hemodialysis patients although cohesion, expressiveness and spouse support had positive effects on the patients' morale. McNett (1987) found that unmarried paraplegics and quadriplegics coped better with their rehabilitation than did those who were married. Hilbert (1985) found no effect of spouse support on myocardial infarction patients' adherence to prescribed regimens. In fact, spouse support had negative effects on physical activity, perhaps because the spouse assumed an enforcer role vis-à-vis the regimen. O'Connor (1983) found that perceptions of health and leisure activities of patients undergoing coronary artery bypass surgery were affected negatively by a spouse's fear of injury. Further, Schafer McCaul and Glasgow (1986) found that adults with diabetes who perceived more negative or non-supportive behaviors from their families were less likely to adhere to their diabetic regimen and had poorer diabetes control than did those reporting fewer nonsupportive family behaviors.

Nursing Support and Chronic Illness

Nursing support for families living with chronic illness, must be considered in the light of the nature of the illness and its demands, and the relationships among the nature, source, and timing of support and the type of outcome.

Illness Demands and Support

The nature of the support available to individuals and their families must be matched to the demands of the illness that they are experiencing. Social support is effective to the extent that it meets the needs of the family either by decreasing these demands, increasing the resources or altering the consequences of failing to manage the demands. *We propose that for specific types of illness demands, there is a specific type of support that is most efficacious.* In particular, for direct effects of the disease such as weakness, instrumental support may be most effective; when there is a threat to self-concept or when there are existential concerns

such as concerns about an uncertain future, emotional and informational support may be most effective. When symptoms produce distress, emotional support may have little effect in reducing the distress. Similarly, instrumental support such as assistance with child care or personal hygiene service cannot be expected to reduce the distress produced by threatened self-concept. The need to shift family roles may best be met by informational and instrumental support, while the need to interpret the illness to children may best be met by emotional and informational support.

Nature and Source of Support

A second consideration in generating protocols is the source of support best suited to provide the types of support needed. *We propose that certain sources of support are most efficacious in providing certain types of support in certain phases of illness.* Information will be perceived by the individual as being most supportive if it is provided by those with whom the individual has weak ties (e.g., health professionals) and when it is provided during the transition phases of the patient's illness. Instrumental support will be perceived by the individual and family as being most efficacious if it is provided by those with whom the family has strong links (e.g., extended family, kin, friends) and when it is provided during a deficit state in the patient's illness. The greater the emotional support provided by those to whom the family has strong links, the greater will be the family's well-being in any phase of illness and the less likely will the family be to perceive a decline in social functioning.

Consideration of the relationship between type of support and potential sources of support provides clinicians and investigators with a basis on which to assess potential support requirements and availability for families. Moreover, consideration of these dimensions clarifies the type of support that professionals from different disciplines can best provide.

Nature and Timing of Support

The joint effects of the nature and timing of support for families must also be considered. Although families experience different demands of illness in different phases of the illness, demands such as dealing with uncertainty about the consequences of the illness may remain fairly constant. As a result, emotional support may be needed throughout the illness; in contrast, assistance in providing physical care may be required more in the early and terminal phases of the illness, and informational support may be more important during transitions. *We propose that the timing of certain types of support will have effects on health outcomes that are contingent on the nature of the illness demands that the individual and family experience.*

Nature and Outcomes of Support

The nature and outcome of support are related, and this relationship necessitates reflection on why support has health effects and what are its direct and indirect relationships to health outcomes. Emotional, informational and instrumental support affects health by altering the demands of illness perceived by individuals or by ameliorating their effects on the health of the person or family. When the outcomes of support to the family are differentiated according to clinical, functional, adaptive and eudaimonistic conceptions of health, it becomes obvious that different types of support are essential. *We propose that the nature of support will have different effects on different types of health outcomes.* The absence of symptoms in the family and low rates of school or work absence signify desired clinical and functional health outcomes. Respectively instrumental, informational and emotional support together probably could sustain families in their activities of daily living. On the other hand, adaptive outcomes (e.g., family cohesiveness and flexibility) could best be fostered by informational and emotional support. Eudaimonistic outcomes

(e.g., feelings of exuberant well-being) perhaps are best served by access to spiritual support. *Moreover, we propose that varying configurations of the nature, timing and source of support will produce qualitatively different health outcomes for chronically ill individuals and their families.* ☞

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